Patient Story

Subject:	Personal Health Budgets (PHB)
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Summary:	A patient's personal perspective of receiving a Personal Health Budget

1. Introduction

Bringing patients or their carers' stories into the Board is welcomed by the Governing Bodies as a mechanism for understanding the impact of the services we commission, positive and negative, on service users. Patient Stories are advocated as a powerful catalyst for change by the Institute for Healthcare Improvement (www.ihi.org).

Patient stories are a key feature of our ambition to revolutionise patient experience. They provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

2. Background

A story was presented to a previous Governing Body meeting which described the impact of the closure of a Nottinghamshire care home on a number of residents and staff working within the home. This story is a follow-up from that story focussing on the experience of a specific individual who was impacted by the home closure.

The story is told from the perspective of a 46 year old woman, Denise, diagnosed with lung cancer. The patient was a resident at Hallcroft Care Home for 5 years up until its owners made the decision to close the home. The owners made this decision due to being unable to recruit a manager and/or registered nurses.

Following an assessment of her needs by the CityCare Continuing Health Care service and completing a support plan to identify her health needs and outcomes, it was agreed that the preferred option for the patient and her husband was to return to the family home with support. An integrated personal health budget (funded by health and social care) was put in place. A personal health budget is an amount of money to support a person's identified health and wellbeing needs. This is planned and agreed between the person and their local NHS team. The aim is to give people greater choice, flexibility and control over their health care and support they receive.

3. The Patient's Story

Denise developed lung cancer in 2011 which spread to other parts of her body, including her brain. Her balance, speech and mobility were all adversely impacted and all parts of her body were affected. Denise had radiotherapy; however the location of the tumour, in the middle of her lungs, made the tumour inoperable.

Denise's illness began with a cough, which was initially treated as acid reflux. She went on to suffer from pneumonia and pleurisy and as the cancer was hidden behind the lungs, it was difficult to detect. At the point Denise's cancer was diagnosed, she was informed that it could not be treated and was offered palliative care and given approximately 12 weeks to live. Denise was moved to Haywood House but as her wish was to die at home a package of support was arranged for her to return. Denise's wish was to be at home with her husband, Andrew and her teenage son. Her husband and her sister initially offered to leave their jobs when she first came home from Haywood House, but this was not necessary and she moved home with the support of carers from an agency. Unfortunately, this did not work out as the care was not consistent and the family felt it lacked compassion, therefore Denise made the difficult decision to move into a care home.

Denise moved from her home into Hallcroft Care Home which was very local to her own home and Andrew visited every day. Her placement was jointly funded by health and social care.

Whilst in Hallcroft, and despite her poor prognosis, Denise made good progress. Her catheter was removed and painkilling medications via a syringe driver pump were discontinued. Denise continued to have a range of health and personal care needs and remained dependent on staff to meet these. She felt that Hallcroft was a good place of care and that the staff were always very professional and caring, although the management of the care home appeared poor. Denise says she liked living at the home, she felt all her needs were being taken care of, which made her feel safe. She was scared about returning to her own home. She had her own room at the care home and carers on hand along with the nurses, as a safety net. However, Denise also says that she spent all day alone in her room with the curtains closed, waiting for Andrew to visit or pick her up to take her home for tea.

When it was known that Hallcroft was closing a meeting was organised with Denise, her family and the social worker. At this meeting a Personal Budget/Personal Health Budget (PHB) jointly funded by health and social care was discussed. Denise was helped to develop a support plan and for the first time she was made aware of her options. The option of a Direct Payment was discussed. This would enable Denise to employ a Personal Assistant to meet all her health and social care needs and outcomes, as identified in her support plan. As the Care Home was closing down, the staff in the home were seeking alternative employment. Denise had a very positive relationship with one particular carer Alison, who was asked if she would be interested in being employed as Denise's personal assistant. With the support plan approved and an integrated personal budget and direct payment in place, Denise moved to her own home when Hallcroft closed.

As Alison already knew Denise's needs it was a perfect fit and has been extremely beneficial for both parties. Alison works 8am - 4pm Monday to Friday and Andrew covers the rest of the time, including weekends. Andrew and Alison work flexibly around each other in relation to cover. Alison supports Denise to attend Leen Valley Care Home twice a week for hoist assisted showers.

The payment process for the care Denise receives has been relatively straightforward. Andrew is supported with employment by a Direct Payment Support Service, who have drawn up an Employment Contract and organise payslips, calculate tax and National Insurance contributions.

Denise has been at home since 17 June 2016 and feels that her life has improved greatly. She is able to get more exercise, whereas in the care home she would sleep all day.

Denise's daytime now consists of greater opportunities to benefit from being at home with her family, including trips to the local town and even being able to go to Goose Fair. Her

husband and son love having her home and part of the family again. Denise says that the best thing is getting back to her family.

The personal health budget has enabled Denise to improve her outcomes, but the cost of her care has reduced. The nursing home cost £556.50 per week and her weekly personal budget has reduced to £409.15 per week, with health paying 30% of the package.

This story illustrates how important it is to ensure that individual's needs are kept under review and that all options for care delivery are considered. It also shows the potential positive impact that PHBs can have on patient outcomes, experience and quality of life. PHBs can also prove a cost effective way of meeting an individual's holistic needs. In order for PHBs to be implemented successfully the importance of helping patients and their families to develop outcome focussed support plans should not be underestimated. It is also recognised that working in partnership with local authority colleagues is essential to assess and meet the health and social care needs of individuals.

We would like to thank Denise and her family for talking the time to share their story with us.

4. Contextual Information and Triangulation with other Data Sources

From 1 October 2014 people who are eligible for NHS continuing health care, including children and young people have had the right to have a personal health budget. The NHS wants more people with complex long term needs to benefit from the option of a personal health budget.

Personalised care and support planning is at the very centre of delivering personal health budgets and more generally is an essential prerequisite for helping people living with long term conditions. It transforms their experience from a largely reactive service, which responds when something goes wrong, to a more helpful proactive service, centred on the needs of each individual patient.

Personal health budgets promote a shift in power and decision making to enable a changed, more effective relationship between the NHS and the people it serves. The personal health budget planning process is not simply a document or template – it is an active, ongoing relationship and dialogue, with changes of role for people, health professionals and commissioners.

The process should explore what the individual needs in their life – this will include an assessment of their health and care needs but move beyond this by understanding that it is not only about the 'disabilities' – it's about the whole person: their strengths, their preferences, their hopes and expectations.

The ability for individuals to employ their own personal assistant (PA) or carer is one of the biggest opportunities presented by personal health budgets. It means that people are able to choose who they want to provide their support and more flexibly control how it is delivered to suit the needs and lifestyle of themselves and their family.

5. Commissioners Response/Action

The NHS planning guidance, 2016/17 – 2020/21 requires all CCGs to develop Sustainability and Transformation Plans and makes clear that personal health budgets and integrated budgets should be included in these plans as a way of handing more power to patients, in line with the mandate commitments.

The most recent shared planning guidance builds on expectations that were outlined in *'*Forward View into action: Planning for 2015/16*':*

"To give patients more direct control, we expect CCGs to lead a major expansion in 2015/16 in the offer and delivery of personal health budgets to people, where evidence indicates they could benefit. As part of this, by April 2016, we expect that personal health budgets or integrated personal budgets across health and social care should be an option for people with learning difficulties, in line with the Sir Stephen Bubb's review. To improve the lives of children with special educational needs, CCGs will need to continue to work alongside local authorities and schools on the implementation of integrated education, health and care plans, and the offer of personal budgets. CCGs should engage widely and fully with their local communities and patients, including with their local HealthWatch, and include clear goals on expanding personal health budgets within their published local Joint Health and Wellbeing Strategy."

Locally the Nottinghamshire Clinical Commissioning Groups (Mansfield & Ashfield, Newark and Sherwood, Nottingham North & East, Nottingham West and Rushcliffe) are committed to increasing the proportion of people eligible for NHS continuing health care who hold personal health budgets, as well as the number of children and young people eligible for an education, health and care plan benefiting from an integrated care budget offering flexibility and choice and incorporating funding for health care from the NHS. The teams involved in assessing people eligible for NHS continuing health care and children and young people eligible for an education, health and care plan have now been trained in personal health budgets and will routinely discuss this option as part of the assessment process.

As well as expanding the number of personal health budgets for those eligible for NHS continuing care the Nottinghamshire Clinical Commissioning Groups will be working closely with Nottinghamshire County Council to improve and expand access to personal health budgets for other groups of individuals with suitable high level needs but who are not eligible for NHS continuing care.

It is important to understand that developing personal health budgets is not about finding new money for additional services but about spending some of the money currently being spent on existing services in a different way. This approach represents a major shift in the way the NHS works and will require comprehensive engagement, careful planning and testing, so as not to compromise the financial sustainability of the NHS or destabilise existing services for other people.

It is likely that early implementation will initially be prioritised for a relatively small group of individuals with suitable high level needs for whom current service offers do not always work well but who are not eligible for NHS continuing care e.g.

- People with learning disabilities or autism in high cost residential placements, or those with high support needs who are frequently using inpatient services, or are at high risk of using inpatient services
- Children and Young People with physical disabilities with complex care packages

In the longer term Nottinghamshire Clinical Commissioning Groups will consult on and further develop processes to enable more people with suitable high level long term needs to benefit from the flexibility, choice and control offered by the personal health budget process, such as:

- Those with complex long term conditions (including neurological conditions) for whom current services do not work well resulting in frequent relapse or crises and access to acute services
- People receiving mental health services who frequently use A&E services
- Young people receiving mental health services transitioning to adult services

The 2017/19 two year NHS Planning guidance submitted in November 2016 required that CCGs published a trajectory of how many PHBs will be reached by year end 2018 and 2019.

This trajectory represents a significant change in expectation for PHB numbers. Whereas previously the NHSE mandate set was to be reached by 2021, the planning guidance clearly set out that PHBs by the end of 2018 must increase to 0.04% per 100,000 population and by 2019 by 0.1%. These trajectories are set out in the table 1 below, along with current numbers per CCG.

CCG	Current PHBs October 2016	By March 2018 (0.04%)	By March 2019 (0.10%)	IPC Target By March 2018 (0.10%)
Mansfield and Ashfield	10	77	193	193
Newark and Sherwood	12	54	134	134
Nottingham North and East	13	61	153	153
Nottingham West	8	39	97	97
Rushcliffe	10	51	127	127
Total	53	282	705	705

Within the Nottinghamshire Sustainability and Transformation Plan an interest was expressed in becoming an early adopter of the Integrated Personal Commissioning (IPC) model. The IPC is one of the pillars of the Five Year Forward View. It empowers people and communities to take an active role in their health and wellbeing with greater choice and control over the care they need. It supports the improvement, integration and personalisation of services, building on learning from personal budgets in social care and driving bold expansion plans for personal health budgets. In Nottinghamshire developmental work for an integrated budget and process for people with health and social care needs is underway, and the IPC aligns to this work. In November 2016 confirmation was received that our bid to become an early adopter had been successful. Being an IPC early adopter means reaching the top figure of 1433 patients on a PHB a year earlier than the mandate. We will need to introduce IPC at pace and scale, cohort by cohort – with goals to scale personalised care planning to 1% of the population, and personal budgets with NHS funding to a minimum

1 in a 1000 by March 2018. The benefits of becoming an early adopter include financial assistance to develop the model; support from specialists at NHSE e.g. finance, decommissioning block contracts and access to a range of support from the Voluntary sector to develop the model. As an early adopter we are expected to achieve the March 2019 trajectory of 0.15% per 100,000 population a year early by March 2018.

Further analysis of the quality and financial impact of PHBs is currently underway but early indications are that expansion of the use of PHBs has the potential for both significant quality improvement and cost effectiveness.

For more information on personal health budgets including responses to frequently asked questions please use the following link https://www.england.nhs.uk/healthbudgets/.

6. Recommendations

The following recommendations are made:

- The Quality Team will continue to increase awareness in regard to the use of Personal Health Budgets
- CityCare Continuing Health Care Service to continue to discuss the option of PHBs at all new and review assessments
- The Quality and Contracting Teams will continue to monitor the use of Personal Health Budgets in line with our objectives identified above
- Continuation of collaborative work with Local Authority colleagues and other stakeholders to ensure we are meeting our goals as outlined in the local Joint Health and Wellbeing Strategy
- Progress work as an early adopter of Integrated Personal Commissioning.

The Governing Body is asked to note the contents of the story and endorse the recommendations made.

7. Update on Actions Taken Following Previous Patient Stories

I. Story presented at January 2016 Governing Bodies: Discrimination experienced by a same sex couple during the birth of their second child.

II. Story presented at March 2016 Governing Bodies: Fetal Care Unit, City Hospital Campus, Nottingham University Hospitals.

Children's Integrated Commissioning Hub and Public Health Nottinghamshire have advised that a Better Births Board has been developed for Nottingham City and Nottinghamshire which will lead the Local Maternity System (LMS) in Nottinghamshire and provide strategic leadership for improvement plans to transform maternity services. The national maternity review Better Births has a real focus on multi professional working, breaking down barriers between professionals to deliver safe and personalised care for women and their babies and improving postnatal care and perinatal mental health.

III. Story presented at July 2016 Governing Bodies: A relative's perspective of services associated with end of life care.

From 1st April 2016 the South CCGs commissioned an End of Life and Bereavement Service from Nottinghamshire Hospice, Cruse Bereavement Care.

Nottinghamshire Hospice offers bereavement support for patients, families and carers of people with life limiting illness:-

- Full assessment of need
- Offers pre-bereavement support
- Offers post bereavement support
- Access to one to one support
- Access to group support
- Access to spiritual support